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## **Parental adaptation to pediatric cancer**

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## SUMMARY

One of the most devastating experiences a parent can encounter is to hear that one's child has cancer. The cancer diagnosis is still often associated with death, although great progress has been made in the treatment of children with cancer over the last 30 years. The use of multi-modality therapy (surgery, chemotherapy, radiotherapy or a combination of these treatment modalities) has led to better chances for survival. Today, long-term survival and cure can be reached for 60-70% of the children. This means that parents live with the hope for cure and an uncertain outcome for long periods of time. At the same time, parents are confronted with intensive and long-lasting treatment of their child that is coupled with distressing side-effects. Some of these side-effects are temporary (such as hair loss), others can be permanent (such as infertility or (neuro)psychological damage).

The purpose of the study, presented in this thesis, is to investigate the psychosocial consequences for parents of the cancer diagnosis and treatment of their child. The predictive contribution of a number of variables to the current psychological functioning and to the adaptation of parents with time will be investigated. Lastly, we have examined whether a structured psychological intervention would have a beneficial effect for parents in coping with the demands of their child's cancer diagnosis and treatment.

Chapter 1 offers a concise *review* of the medical aspects of cancer in children. The short- and long-term consequences of the illness and the treatment for the ill child and the parents will be discussed. The *theoretical background* of the study is delineated, focussing on the constructs of stressor, personality, coping and social support in relation to psychological functioning. Attention is given to the relation between psychological functioning and variables that are considered to change as a consequence of the stressor versus variables that are considered to be (relatively) stable.

Chapter 2 describes the *prevalence of psychosomatic complaints* (as measured

by the Symptom Check List) and the level of *psychological distress* (as measured by the Goldberg General Health Questionnaire) of fathers and mothers at the time of the diagnosis, and 6 and 12 months later. Both fathers and mothers report the most psychosomatic complaints and highest levels of psychological distress at diagnosis. The prevalence of complaints and the level of distress decline during the year. While parents report similar amounts of psychosomatic complaints as a normative group at twelve months, their level of psychological distress is still significantly higher than that of a normative group. In general, women indicate experiencing more complaints and higher distress levels than men. However, fathers and mothers of pediatric cancer patients are similar with respect to their reported prevalence of psychiatric complaints and level of psychological distress at different points in time during the first year after the cancer diagnosis. There appear to be only a few differences between fathers and mothers in the frequency with which they make use of seven conceptually different coping styles. Fathers make significantly more use of active problem focussing at the time of the diagnosis, and less use of a palliative reaction pattern at 12 months after diagnosis than do mothers. Mothers make more use of seeking social support during the year than do fathers. There was a tendency within couples for similar, rather than for discrepant use of the different coping styles. However, when partners used the different coping styles more discrepantly then fathers reported greater distress shortly after diagnosis, while mothers reported more distress at 12 months.

Chapter 3 addresses the frequency of use by fathers and mothers of the seven *coping styles* during the year following a child's cancer diagnosis. Fathers use six of the seven coping styles less frequently with time, and mothers four of the seven. At diagnosis, parents make more use of social support seeking, and less use of expression of emotions and comforting cognition than a comparison group of people who are confronted with everyday problems and events, but not with a cancer diagnosis. At twelve months, parents make less use of active problem focussing, a

palliative reaction cognition. The results show that use of the different coping styles is related to psychological functioning. In the use of coping styles, fathers and mothers show different psychological distress levels. This is a significant factor for mothers. Fathers who used a palliative reaction pattern reported higher levels of distress.

Chapter 4 discusses the level of *dissatisfaction* reported by fathers and mothers at different points in time during the first year after the cancer diagnosis. Fathers report significantly lower levels of dissatisfaction than mothers. Parents indicate that the level of marital dissatisfaction is a significant predictor of the level of psychological distress. We found that the level of marital dissatisfaction significantly affects the level of psychological distress. In contrast, mothers' use of coping styles is not a significant predictor of their psychological distress.

Parents of pediatric cancer patients report a significant level of dissatisfaction at the time of diagnosis. Vast majority of parents report a significant amount of dissatisfaction. Fathers report a significantly higher amount of dissatisfaction than mothers. They receive more social support than mothers. They receive more information than mothers. They receive more information than mothers. Mothers are equally satisfied with the information they receive. Analyses with respect to the contribution of social support to the level of dissatisfaction showed that fathers who received more social support reported lower levels of dissatisfaction. Mothers who received more social support reported higher levels of dissatisfaction.

palliative reaction pattern, avoidance, expression of emotions and comforting cognition. The results underline that coping is a situation-specific process. Fathers' use of the different coping styles at diagnosis is a significant predictor of their future psychological functioning; this is not found for the mothers. Changes during the year in the use of coping styles are significantly associated with changes in levels of psychological distress of both parents. A passive reaction pattern is a consistent risk factor for mothers. Fathers, who, apart from this last mentioned coping style, also used a palliative reaction pattern, avoidance, and expression of emotions more often, reported higher levels of distress.

Chapter 4 shows that there is an increase over the year in *marital dissatisfaction* reported by the parents of pediatric cancer patients. However, the level of marital dissatisfaction is comparable to that of a normative group, and significantly lower than that of couples seeking marital therapy. While 43% of the parents indicate to be more dissatisfied with their marriage, 20% report less dissatisfaction. We also examined the relationship between use of the coping styles and the level of marital dissatisfaction. Use of different coping styles by the fathers significantly affects their own level of marital distress *and* that of their partners. In contrast, mothers' use of coping does not affect their own level of marital distress *nor* that of their partners. A discrepant use within a couple of emotion-regulatory coping is a significant predictor of the marital dissatisfaction of both parents.

Parents of pediatric cancer patients receive the most *support* (chapter 5) at the time of diagnosis. While the quantity of support received declines over the year, the amount of dissatisfaction with support remains unchanged. Mothers only indicate they receive more support than fathers do at 6 months post-diagnosis. Fathers report they receive more negative support than mothers do at 6 and 12 months. Fathers and mothers are equally (dis)satisfied with the support they receive at all measurement times. Analyses were performed to examine the concurrent and prospective contribution of social support to the level of psychological distress. We also



examined the extent to which change in support was related to change in levels of distress. Social support appears a significant predictor of paternal levels of psychological distress but not of maternal levels. Fathers, who are more dissatisfied with the support they receive and those who indicate they receive more negative support, show higher levels of distress. Mothers, who are clinically distressed at diagnosis but who are doing well psychologically 12 months later, receive more support at diagnosis and are less dissatisfied with that support than mothers who remain clinically distressed over the year.

Chapter 6 examines the extent to which (a) *demographic variables, other life-events, illness variables*, (b) *personality*, (c) *coping styles* and (d) *social support*, as measured at diagnosis, predict parental levels of distress 1 year post-diagnosis. It also shows which of the initial variables are the strongest predictors of future distress. Stable variables were first placed in the model, the changeable variables in the following step. Four separate prospective analyses have been performed including first the variables mentioned in (a), then (b), (c) and lastly (d). These prospective analyses indicate that demographic and illness-related variables together with the number of life-events experienced by the parents prior to the cancer diagnosis do not significantly predict parental levels of distress at 1 year. Initial personality characteristics, coping styles and social support significantly predict paternal levels of distress at 1 year, but not maternal. The second series of analyses examine the association between changes in levels of distress and changes in predictor variables. The number of other life-events experienced by the parents during the first year of treatment and the physical response of the child to the treatment appears unrelated to parental level of distress at 1 year. Changes over the year in personality and in coping styles are significantly associated with changes in level of distress of both fathers and mothers. Changes in social support were associated with changes in paternal level of distress only. The last analytical model involved the variables with a unique contribution to fathers' or mothers' level of distress, identified in the former two

series of analyses. to be the personality and the coping styles dissatisfaction with fathers, the strongest additional predictors more positive even 1 year. An increase during the year are

The effect of guided intervention months after diagnosis psychologist. Cognitive Individual variation developmental stage was in addition to analyses show no psychological function dissatisfaction with the intervention just

The final comparison and a comparison are discussed.

series of analyses. The strongest predictor of a fathers' future level of distress appears to be the personality character trait anxiety, followed by dissatisfaction with support and the coping style "seeking social support". Also an increase in trait anxiety and in dissatisfaction with support over the year are strong predictors. Similar to that of the fathers, the strongest predictor of mothers' distress level at 1 year is trait anxiety. An additional predictor is the number of positive events. Mothers who have experienced more positive events during the year prior to diagnosis report higher distress levels at 1 year. An increase in trait anxiety and a decrease in frequency of assertive behaviour during the year are further predictors of higher levels of maternal distress.

The effect of an *intervention program* is examined in chapter 7. The manual-guided intervention consisted of eight 90-minutes sessions during the first six months after diagnosis. Meetings involved the parent(s) of one child and the psychologist. Cognitive-behavioural techniques and psycho-education were used. Individual variation was possible. For example, discussion could be adjusted to the developmental stage of the child. The intervention was offered to 39 parents, and was in addition to standard care, which was received by 42 parents. Statistical analyses show no demonstration of beneficial effects of this intervention on parental psychological functioning, on the intensity of negative and positive emotions or on dissatisfaction with support. A clinical evaluation indicates that parents who receive the intervention judge the intervention to be positive and helpful.

The final chapter (chapter 8) includes a summary of the results of this thesis, and a comparison of these results with the literature. Implications for future research are discussed.